



Call to Action:

Strategic Steps for Real Change



2009 Study Results from the
Workgroup on the Future for
People with Severe Developmental
Disabilities, including Autism



Action Plan Priorities:

What We Can Do



Increasingly, people with severe developmental disabilities and their families in Montgomery County find themselves in crisis, without the services, support and information they require. In a companion document, **PARTNERSHIPS FOR A POSITIVE FUTURE: STUDY RESULTS FROM THE 2008 WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM**, available at <http://www.montgomerycountymd.gov/hhstmpl.asp?url=/content/hhs/ads/disabilitysite.asp>, the *Workgroup on Severe Developmental Disabilities, including Autism* provides detailed information on the situations people face in Montgomery County. Their findings and recommendations are consistent with several recently published statewide and national reports looking at the same issues, which are referenced in the companion document.

Almost all of the recommendations that follow can be accomplished at little or no cost. Those that may require a funding allocation are denoted by the symbol **\$\$\$**. Also, recommendations are organized by suggested implementation priority, and are listed under Year 1 or Year 2 headings.

PRIORITY 1. Respond proactively to people in crisis who are on waiting lists, and advocate for more services and options.

There are urgent needs to provide some level of support to people on waiting lists and to build the service system's capacity. Added capacity would increase the number of children and adults served, enhance the expertise of service providers who work with people with severe developmental disabilities, and expand the ability of community services that serve the general population to successfully include people with severe developmental disabilities.

Recommendation

YEAR 1

- ⦿ Establish a cross-departmental County workgroup, with broad representation of public and private stakeholders and advocates, to develop strategies for addressing the needs of the children and adults who are languishing on waiting lists for services. This workgroup's charge would be to (a) analyze options for employment, therapeutic and recreational support in the County so as to open

doors for people while they are on the waiting list and during gaps in services; (b) advocate with the State to maximize waiver funding, utilize all allocated funds, and reallocate unused funds; (c) maximize the use of existing specialized and general services, introducing universal design to increase accessibility for people with disabilities; (d) advocate with the State to evaluate the waiting list for the autism waiver so that these highly specialized services are targeted to people whose support requirements cannot be met in any other way and so that children need not rely on funding from the adult system, further stretching those limited resources; (e) advocate for insurance coverage for therapeutic support for people with autism; (f) advocate for different caps on autism waiver services to enable the funding to reach more children and families; (g) advocate for adequate funding for students who transition from school to adult services, with incentives for serving adults with severe disabilities; and (h) remove barriers that prohibit many students with severe disabilities from participating in after-school sports and extracurricular activities (e.g., students may be considered academically ineligible by County standards and may require specialized accommodations or supports, which may or may not require funding).



PRIORITY 2: Provide support for people through service and life cycle transitions, while ensuring that they move into activities and services that are meaningful and that enable them to learn, grow and contribute.

There is an **urgent** need to support people with severe developmental disabilities so that they spend their time in ways that are meaningful to them. Also, they require strong support through transitions, especially as young adults exit school, so that they transition into challenging post-secondary education and/or productive employment, with the support, services, and high expectations for active participation in community life.

Recommendation

YEAR 1

- ① Create and implement systems, processes and incentives to ensure collaboration between Montgomery County Public Schools and adult service agencies that serve people with disabilities and their families, with guidance by the County Transition Taskforce.

- ⦿ Expand the number of County staff that support families in navigating the transition process in the Montgomery County Public Schools and Department of Health and Human Services. \$\$\$
- ⦿ Work through local workforce development initiatives to create and/or include employment opportunities for people with severe developmental disabilities within the business community and within County and incorporated city governments.
- ⦿ Create and promote internships for people with severe developmental disabilities and remove barriers to employment within the County and incorporated cities.
- ⦿ Develop partnerships with public and private sector employers to create job opportunities, internships, career explorations, and situational assessments, leading to supported and customized employment.
- ⦿ Identify and advocate for flexible program models that work for people with severe developmental disabilities with flexible funding for services and approaches that allow for a mix of work, education, recreation, therapeutic support, and other activities, redefining current funding formulas to make this possible.
- ⦿ Increase access to continuing education at Montgomery County Community College with supports and accommodations, to increase the likelihood of productive meaningful employment and more independent community living for people with severe developmental disabilities.

YEAR 2

- ⦿ Develop a pilot project to measure transition success for students with disabilities, including employment outcomes, post-secondary education, and how well they were prepared for adulthood.



PRIORITY 3: Increase support to families across the lifespan.

Support is broadly defined and includes increasing the ease of access to timely, relevant information for families, people with disabilities and the people who support them. Support must also address the devastating financial impact on families. Having a family member with a severe disability creates severe economic hardships due to lost individual and family income, out-of-pocket expenses, and increased medical and therapeutic costs.

Recommendation

YEAR 1

- ⦿ Augment *Info Montgomery* and use Montgomery County's Health and Human Services Regional Center staff and volunteers through the Volunteer Center so that they provide targeted information related to support for people with developmental disabilities and their families, with continuous updating and training for the people who receive calls and requests for information.

YEAR 2

- ⦿ Broadly advertise and market *Info Montgomery*'s capacity to assist families, people with disabilities and the people who support them, with outreach to ensure that people throughout the County know how to access information. \$\$\$
- ⦿ Develop a formal family-to-family support program to inform and prepare people with developmental disabilities and their families for the realities of transitions across the lifespan. \$\$\$
- ⦿ Create and support additional before and after school and adult program options, as part of typical inclusive services, in inclusive settings wherever possible, with accommodations and support, to enable parents to maintain employment while offering meaningful activities for their family member with a severe developmental disability. \$\$\$
- ⦿ Extend the Working Parents Assistance program to age 21 for adolescents with significant disabilities. \$\$\$



PRIORITY 4: Increase the number of highly-skilled, responsive, and adequately paid people to provide direct support, medical, dental and therapeutic services.

The workforce charged with serving people with severe developmental disabilities must be dynamic, diverse and strong. This professional workforce includes direct support staff; mid-level managers; and medical, dental and therapeutic staff.

Recommendation

YEAR 1

- ⦿ Revise current policy/legislative language to develop more customized service options that can be charged to Medicaid, including services such as nutrition, thereby expanding the array of available services.

YEAR 2

- ⦿ Develop a *pro bono* or low cost dental pool for dental services that are not covered by Medicaid or standard insurance.
- ⦿ Design and implement creative approaches for building capacity for therapeutic, medical and dental services and direct support to people with severe disabilities, both to expand the availability of services and the number of providers with expertise in working with people with severe developmental disabilities.
- ⦿ Create incentives or fund subsidies to attract people into therapeutic fields (including speech/language therapy, physical therapy (PT), occupational therapy (OT)). \$\$\$

PRIORITY 5: Identify and utilize the full array of community services and support available to all County residents.

This priority will build community capacity and both promote community inclusion and lessen the current total dependence on specialized services and supports. Accommodations should be provided as necessary.

Recommendation

YEAR 1

- ⦿ Implement House Bill 1411, the Fitness and Athletics Equity Act for Students with Disabilities, which promotes equal access to recreational and physical education

programs for children with disabilities. The bill creates policies and procedures to promote and protect the inclusion of students with disabilities into mainstream physical education and athletic programs, extracurricular activities, and interscholastic competitions.

- ⦿ Identify typical community services and supports available in the County to all of its residents that can be made accessible to people with severe developmental disabilities of all ages, prioritizing these for people on a waiting list for services.
- ⦿ Provide supplemental funding to support capacity-building for typical childcare providers, including training and consultation. \$\$\$
- ⦿ Increase the funding allocation in the recreation department to support therapeutic recreation and inclusion support for people with disabilities. The current allocation for therapeutic recreation is 3.6% , even though the percentage of people with severe disabilities is over 12%.

These conclusions and the recommendations in our companion document, **PARTNERSHIPS FOR A POSITIVE FUTURE : STUDY RESULTS FROM THE 2008 WORKGROUP ON THE FUTURE FOR PEOPLE WITH SEVERE DEVELOPMENTAL DISABILITIES, INCLUDING AUTISM**, are consistent with those of the Arc of Maryland. In their 2008 Public Policy Platform, they advocate for (1) a multi-year Waiting List Initiative to meet the needs of individuals on the DDA Waiting List and Autism Waiver; (2) building the capacity in the community to serve and include people with developmental disabilities; (3) full funding for the Transitioning Youth Program; (4) supports that lead to self-determination and inclusive lives for people with developmental disabilities; and (5) adequate funding to ensure a stable, quality system of community programs, including residential, employment, vocational and individual and family supports (The Arc of Maryland. (2008). 2008 Public Policy Platform. <http://www.thearcmd.org/files/6read-here.pdf>).

For more information about these reports, please contact :
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For Maryland Relay call 711.

Definitions



Autism Spectrum Disorders (ASDs). This group of developmental disabilities is defined by significant impairments in social interaction and communication and the presence of unusual behaviors and interests. Many people with ASDs also have unusual ways of learning, paying attention, or reacting to different sensations. The thinking and learning abilities of people with ASDs can vary—from gifted to severely challenged. ASD begins before the age of three and lasts throughout a person's life. It occurs in all racial, ethnic, and socioeconomic groups and is four times more likely to occur in males than females. (Centers for Disease Control and Prevention (CDC): Autism Information Center, <http://www.cdc.gov/ncbddd/autism/index.htm>).

Developmental Disability. This term (as defined by the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402) refers to a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination thereof.
2. Is manifested before the individual attains the age of 22.
3. Is likely to continue indefinitely.
4. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency.
5. Reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized support, or other forms of assistance that are of lifelong or of extended duration and are individually planned and coordinated.

Family Support. This term refers to resources, subsidies, services, and other assistance provided to families of persons with disabilities that are designed to support families in their efforts to maintain family members with disabilities at home, strengthen the role of the family as primary caregiver, prevent inappropriate and unwanted out-of-home placement, maintain family unity, and connect families with persons with disabilities who have been placed out of the home, whenever possible. The term includes service coordination, goods, services and financial assistance.

Intellectual Disability. This is a disability characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18 (American Association for Intellectual and Developmental Disabilities). Intellectual disability is characterized both by a significantly below-average score on a test of mental ability or intelligence and by limitations in the ability to function in areas of daily life, such as communication, self-care, and getting along in social situations and school activities. Intellectual disability has historically also been referred to as a cognitive disability or mental retardation (Centers for Disease Control and Prevention (CDC): National Center on Birth Defects and Developmental Disabilities, <http://www.cdc.gov/ncbddd/dd/ddmr.htm>, 2005).

Severe Developmental Disability. There is not a single definition for severe developmental disability, as definitions tend to be specific to what a person's unique disability may limit. For the purposes of this report, a severe developmental disability is one that creates significant barriers to one or more of an individual's abilities (such as mobility, learning, communication, self-care, self-direction, interpersonal skills, work tolerance, or work skills) so that the individual requires intensive and continuous long-term support.

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